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A Framework for Post-Stroke Quality of Life Prediction using Structured Prediction

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Abstract—This paper presents a conceptual model that relates Quality of Life to the established Quality of Experience formation process. It uses concepts developed by the Quality of Experience community to propose an adapted framework for developing predictive models for Quality of Life. A mapping of common factors that can be applied to health related quality of life is proposed and practical challenges for modelling and applications are presented and discussed. The process of identifying and categorising factors and features is illustrated using stroke patient treatment as an example use case.

Keywords—*Quality of Life, Quality of Experience, QoL, QoE, Stroke, Structured Prediction*

I. INTRODUCTION AND MOTIVATIONS

Clinical studies of stroke patients commonly use quality of life measurements as a standardised endpoint to evaluate post-treatment or rehabilitation endpoints. It is generally accepted by healthcare professionals that patients who have suffered a stroke are never ‘fully cured’ and that quality of life (QoL) should be considered when assessing the benefits of a given treatment. Nowadays, patients tend to have greater input into their treatment plans with healthcare professionals providing fuller information about expected longer term outcomes. This trend aligns with the WHO definition of health [1] that has not changed since it was developed in 1946. It states:

“Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”

Present day healthcare has been revolutionised by information technology. Electronic health records use structured data to capture patient related data across wide-ranging data types [2] including medical histories, medication, laboratory results, medical imaging and genomics. Other more general data can help to put patient quality of life outcomes in context of population norms, e.g. social, lifestyle and gender data; economic and work-life data.

This data can be leveraged to aid in the treatment of stroke trauma by applying data mining, natural language processing and machine learning to develop clinical decision support (CDS) systems. As a first step, a discussion and shared understanding of QoL in the context of healthcare, and its underlying concepts, need to be developed between the patient, healthcare professional and technologist stakeholders.

Patients are now evaluating treatment outcomes in a broader context and looking more at the non-clinical aspects

of treatment than healthcare professionals did in the past [5]. The success of a treatment is reviewed in conjunction with a patient’s medical history, life context and expectations to develop a shared understanding of QoL between all stakeholders from patients and healthcare professionals to researchers across disciplines, funding bodies and ethical review committees.

This paper seeks to build on work by the QUALINET EU COST Network where an exercise was undertaken to define the term Quality of Experience (QoE) and its related concepts. This led to a white paper [6] describing QoE and applying it to the field of multimedia quality as a use case.

We will review the literature on QoL and evaluate whether the framework developed for QoE assessment can be re-applied to QoL. In the same way that the QoE whitepaper is illustrated using the multimedia communications domain as a concrete example, this paper will focus on QoL with respect to stroke patients. While the definition of QoL for stroke patients is used to illustrate the proposed adaptation of QoE to QoL, the authors believe the mapping process and framework is equally applicable across all health related QoL.

The aim in this paper is to contribute to a fundamental common understanding for QoL as a multi-faceted data component. Technologists and data scientists should be able to apply predictive analytics to leverage clinical data and surveys in order to predict complex multifaceted QoL outcomes. Applying computer modelling to the large amounts of health-related data already collected and archived will facilitate the development of better treatments and personalised patient therapies. The QoE community should see this as an example, in a different domain, building upon their efforts in developing a generic framework for QoE assessment. Recently, QoE has been applied to a range of fields including olfactory evaluation [7] and gaming [8] and extensions have been proposed to predict behaviour based on QoE [9]. While we have substituted QoL for QoE, we believe the fundamental framework developed by the QoE community can be re-applied to the health domain to develop QoL prediction models.

The stroke treatment community in particular is looking for ways in which technology can reduce the human and economic burden of stroke. In the 27 EU countries, total annual cost of stroke is estimated at €27 billion [10]. This spans €18.5 billion (68.5%) for direct and €8.5 billion (31.5%) for indirect costs and a further sum of €11.1 billion for informal care.

This paper reviews the concept QoE and maps QoL to the QoE formation process. The factors and features of quality of life for patients post stroke treatment are then used to create a

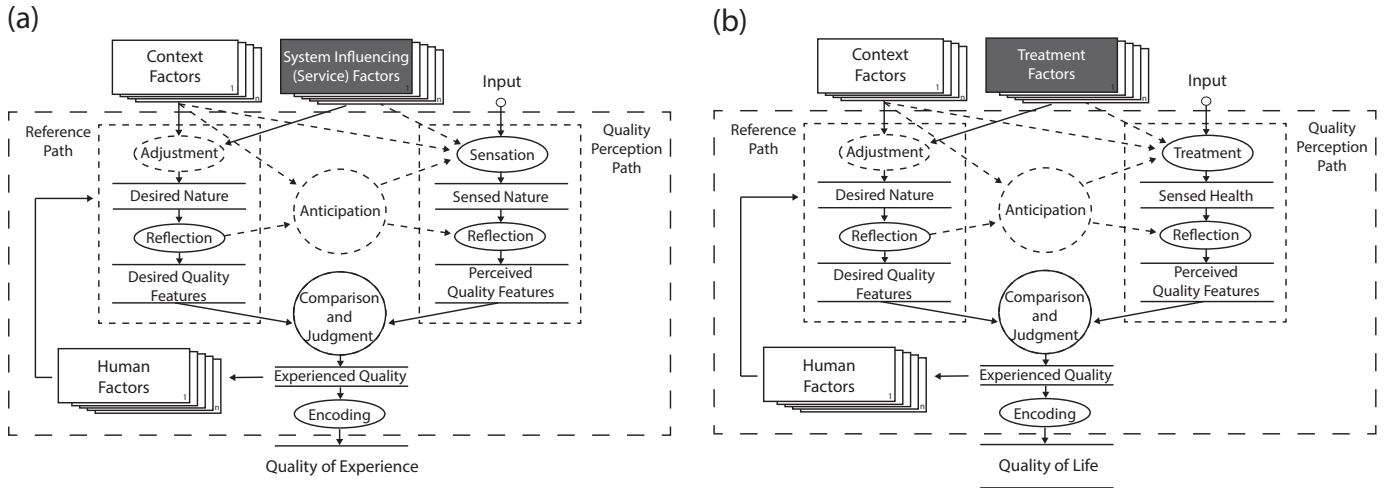


Fig. 1. QoE and QoL block diagrams. (a): QoE diagram derived from Jekosch [3] and Raake [4] with Context and System Influencing Factors split as separate factors. (b): QoL mapped to QoE block diagram with treatment substituted for System (or service) factors, sensed health and treatment in the quality perception path and QoL as the output.

QoL data structure, which is proposed as an output for a CDS system. Finally, conclusions and future work are discussed.

II. ADAPTING THE QoE FRAMEWORK FOR QoL

A. Building from Quality of Experience

Prior to attempting to develop a definition for QoL, a review of the approach taken to defining QoE was seen as a useful exercise. A working definition is provided as:

Quality of Experience (QoE) is the degree of delight or annoyance of the user of an application or service. It results from the fulfilment of his or her expectations with respect to the utility and / or enjoyment of the application or service in the light of the user's personality and current state.

Consideration is given to a number of important aspects. Firstly, the service is inextricably linked to human factors, i.e. the expectations of the user and the degree of success (delight or annoyance) must be adapted to an individual user's expectations prior to the experience. Secondly, the prediction includes the complete end-to-end system effects, i.e. it is not a just a service or system metric and includes context regarding the environment and user. This is illustrated in Figure 1 where the context, system and human factors all form part of the QoE formation process.

The concept of *meaning* in relation to the definition of QoE [6, pp.6–7] highlights that in the case of QoE for media (e.g. a video) transmitted over a network, the original media may reflect an artist's or content producer's effort to "create experiences ... to deliberately achieve pre-determined user experiences." This implies that *meaning* is related to the creator's intentions but will be perceived through the perspective of the content consumer, as noted by Jekosch [3]. The whitepaper states that

"QoE does not explicitly address the degree of success achieved by an artist or creator to convey

the intended message, but rather how a technical system or technical processing may have positively or negatively affected the success of conveying an artistic or of another (e.g. speech) message." [6, 7]

In the process of developing the working definition for QoE, the whitepaper defines the terms *quality* and *experience*. It emphasises an understanding of these terms from the perspective of an individual, e.g. the definition of experience as "an individual's stream of perception and interpretation of one or multiple events" and quality as "the outcome of an individual's comparison and judgement process". Quality is considered "in terms of the evaluated excellence or goodness, of the degree of need fulfillment, and in terms of a 'quality event'" (see Martens & Martens, 2001, and [3]) rather than as a set of inherent characteristics or '*qualitas*'.

In formalising the concept of QoE, the definition was explicitly designed to be applied to new domains as it is seen as "a concept that it is not only limited to the use of a system or service, as it is also related to the content itself" [6, p.2]. The authors assert that while "the QoE definition and related concepts and definitions may be driven by multimedia services and systems, it is expected that they shall also be applicable beyond." [6, p.3]. They go on to suggest that

"different application domains may have different requirements in terms of QoE. Thus, there is a need to provide specializations of a generally agreed definition of QoE ... Consequently, an application-specific QoE definition is provided by selecting the influence factors and features of QoE reflecting the requirements of the application domain and incorporating them into the generally agreed definition of QoE." [6, p.10]

B. Health Related Quality of Life

QoL has proven to be an ambiguous and elusive concept as it is used widely across many fields [11]. From a health per-

spective, QoL is given two alternative definitions, depending on context, by Fayers and Machin [5]: (a) the set of outcomes that contribute to a patient's well-being or overall health, or (b) a summary measure or scale that purports to describe a patient's overall well-being or health. From a healthcare perspective, QoL is usually measured post-treatment using patient surveys. The US Centre for Disease Control uses a set of questions called the "Healthy Days Measures" [12] although many tailored surveys exist. The questions include measures of physical and mental health and their impact on your activities over a 30 day period, capturing your perceived QoL and taking into account a range of contexts.

The definition and measuring methodology show that evaluating a variety of perceived outcomes contribute to QoL but that it is also sometimes distilled into a summary aggregate scale. Adapting to an individual user's expectations as well as including context are important to QoL evaluation, just as they are for QoE. It is clear that measuring QoL via a survey is a retrospective evaluation, in the same way as QoE is formed after experiencing an event. However, in the same way that models have been developed to predict QoE, having access to a predicted QoL prior to treatment would be a valuable addition to clinical decision-making.

Physicians and patients carry out an informal QoL assessment prior to treatment today: the patient's full history is taken, the patient's and physician's expectations are discussed to build an understanding of their personal situation and this information is synthesised with the clinical test results to provide treatment options and the potential post-treatment QoL. Post-treatment, surveys can establish the actual QoL.

We have mapped the QoL formation process (Figure 1b) to the QoE formation process (Figure 1a). Most of the formation process pathways remains the same with human factors and context factors impacting QoL. The main difference is substitution of the concept of system or service factors with treatment factors. QoE apportions a quality value judgement on an application or service, and Möller [13] gives the influencing factors for a communications network as "content, network, device, application user expectations and goals, and context of use." In QoL, the treatment (or therapy) is substituted for the service (or system) as a factor. The concept of a *reference path* reflecting the temporal and contextual nature of the quality formation process is maintained as QoL will inherit a memory of former life experience, forming a feedback loop from the experienced quality. The *quality perception path* takes the perception of a physical event's effect, and is triggered by the execution of an input, e.g. a treatment or therapy.

Evaluating the success of a patient's clinical treatment or rehabilitation in isolation of their expectations can be seen to be analogous to quality of service (QoS) in media terms. In the same way that QoE can be low, despite system factors indicative of a high QoS, a surgeon could perform an operation that was technically 100% successful in its clinical outcomes but the overall QoL will be tempered by patient context e.g. their robustness in terms of general health, age, etc. It also echoes the concept of a content creator's *meaning* being evaluated from the perceiver's perspective in QoE. In QoL terms, while a procedure (treatment or therapy) may have fulfilled the healthcare professional's definition of success, the patient will perceive the outcome through the lens of QoL.

This concept can be understood as: QoL does not explicitly address the degree of success achieved by an doctor or healthcare professional in executing the intended treatment, but rather how a therapy or treatment may positively or negatively affected the QoL expectations projected from a post-treatment perspective. This is discussed further in Section III using stroke treatment as an example use case.

III. DEFINITION OF ST-QoL

Currently, when a person suffers a stroke and is brought to hospital they are assessed using a range of measures, including lab data, medical imaging, patient history, their functional status, etc. The clinician must assimilate this array of data and then choose the appropriate treatment for the patient. Post-treatment, the QoL of a patient is often assessed to gauge the overall success of the treatment. Our long-term research target is to develop a CDS system that takes as input the range of patient information generated during the patient assessment process and provides as output a prediction for each treatment outcome, the likelihood of that outcome and the QoL related to that outcome. In a trauma stroke treatment context when a clinician is selecting the treatment for a patient, we believe that providing the clinician with these predictions would help during treatment selection.

We have developed the concept of quality of life post stroke treatment (ST-QoL) to describe the relationship between the outcome of a given stroke treatment and the quality of life experienced by the individual. The ST-QoL definition we set out in this section is the blueprint for the data structures that our planned CDS system will output. Figure 2 illustrates how predicting ST-QoL for each treatment and outcome combination fits into the general stroke treatment process.

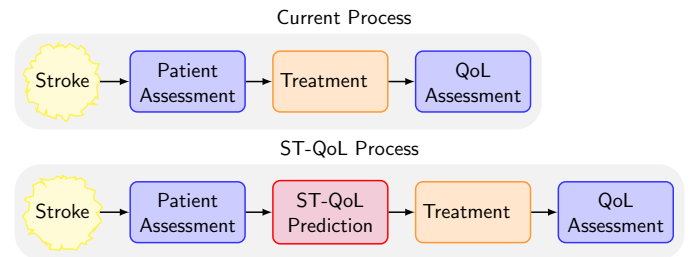


Fig. 2. Integrating ST-QoL Prediction into the Stroke Treatment Process

In developing the ST-QoL concept we have used the concept of QoE to frame the relationship between treatment and QoL. In the previous section we discussed how the influencing factors defined in the QoE framework (Service, Human and Context) map to the clinical domain: the concept of Service can frame the clinical treatment; Context frames the social and economic context of the patient; and Human frames the physical and psychological abilities of the patient. This mapping is useful because it highlights how different levels of service (or in the clinical context different treatment outcomes) interacts with both Human and Context factors in constructing the individual's experience of their QoL post stroke. In this section, we unpack the structural relationships between these factors and discuss how these high-level factors can be decomposed in measurable quantities.

Figure 3 illustrates the structure of ST-QoL concept. The goal of this figure is to provide decomposition of the high-level ST-QoL concept to a granularity of measurable quantities. This decomposition enables a data driven assessment of an individuals post stroke treatment QoL with the longer term potential to open the possibility of data driven prediction of stroke treatment QoL outcomes for patients. Furthermore, we believe that a QoE informed approach would be useful in defining post-treatment QoL for a range of diseases. We have highlighted (using a grey background in Figure 3) the nodes that represent stroke specific post-treatment QoL factors. Our motivation for this highlighting is to illustrate how the QoE framework can inform the modelling of post-treatment QoL for diseases other than stroke. Applying the QoE framework to other diseases would involve replacing these stroke factors with factors relevant to the new disease.

The initial decomposition of the ST-QoL concept is in terms of the influencing factors defined in the QoE framework, with the slight modification in that here the term Treatment is preferred to Service. The Treatment concept captures information relating to the type of treatment the patient received, the outcome of the treatment (was it a success), and the probability of that outcome for that treatment given the patient's condition. Indicative values for the treatment Type attribute include *medication*, *surgery*, etc. We envisage the Outcome attribute being measured using a scale such as the modified Rankin Scale (mRS) [14]. The mRS scale is the most frequently used measure of outcomes in stroke clinical trials. The scale runs from 0 to 6 with a value of 0 indicating *no symptoms* and a value of 6 indicating *death*.

Traditionally, in a clinical setting QoL was often narrowly defined and focused on measures of morbidity or mortality. Since the 1980s, however, there was a growing recognition of the need to include patient centred measures in clinical trials and this has led to development of the concept of health-related quality of life (HRQoL). HRQoL is used to broadly describe QoL, including physical, psychological, and social aspects of an individual's life that have been shown to affect health. Together the Health and Context factors capture this broader conceptualisation of HRQoL.

Measurements of HRQoL are often survey based. These surveys can be classified as generic or disease specific. Well known generic measurements of health include the short-form health survey (SF-36) [15] and EuroQoL [16]. We are interested in stroke treatment and so we have focused on surveys that are designed for stroke. The Stroke Specific Quality of Life survey was designed for use in stroke clinical trials [17]. The survey was developed through a set of interviews with 32 post-stroke patients and identified 12 life domains that are commonly affected by stroke. These domains spanned the physical, psychological and social aspects of people's lives. The domains included energy levels, mobility, upper extremity function (UEF), vision, ability to self-care, personality, thinking, language, family roles, social roles, and work/productivity. The Stroke Specific Quality of Life survey defines measurement scales for each of these domains in terms of Likert Scale questions.

Within the QoE framework the Human Influencing Factors cover all human characteristics, including their physical, mental and emotional state, and their demographic and socio-

economic background. The Context influencing factors include any properties that describe the individual's environment, including physical, temporal social, economic etc. For our purposes there is an overlap between these sets of influencing factors, for example both sets include social and economic indicators. We distinguish between Human factors and Context factors by defining the Human factors as only those factors that are intrinsic to the individual in a narrow sense, namely: the physical, mental and emotional state of the individual. Using this definition we define the decomposition of the Human Influencing Factor to include measurements of an individual's mobility, upper extremity function (UEF), vision, ability to self-care, personality, and thinking. The Context Influencing factor then includes the other Stroke Specific QoL domains including family roles, social roles and an individual's work.

Finally, as populations age and more individuals survive stroke events, there is a growing awareness of the increase of the economic burden of post-stroke care [10]. Some of these care costs are borne by the family and social network of an individual. These hidden costs are important but are difficult to quantify. In this context it is important to consider the economic cost of post-stroke care for a patient in light of the treatment they received and the outcome of that treatment. In order to capture this we have extended the decomposition of the Context concept to include a measure of Care Costs.

IV. PREDICTING ST-QoL

A long-term goal for our work is to develop CDS system to aid in the treatment of stroke trauma. Ideally, this system should take as input a detailed patient profile and then generate a set of predictions that are useful to the clinician in deciding which treatment is most appropriate for the presenting patient.

In defining this system we build on the definition of ST-QoL that we developed in the preceding section. In particular, we envisage that the system will generate a separate ST-QoL structure for each treatment and outcome combination. Generating this set of predictions will enable the clinician to compare treatments in terms of both the likelihood of each outcome and the QoL profile associated with each outcome.

Our preferred methodology for developing this system is to frame the problem as a machine learning prediction task where predictive models are trained from datasets of previous patients records and outcomes [18]. The development of such a data driven system pre-supposes the definition of the structure of the desired dataset. A frequently used process for developing this data definition is to decompose the overall prediction task into a set of high-level domain concepts which are then further decomposed in concrete features that can be included in the dataset. Figure 4 illustrates the decomposition of the post-stroke treatment QoL prediction task (PT-QoL) that we have developed.

As we indicated above the output for this system is a set of ST-QoL structures, one structure for each treatment and outcome combination. This complex output is represented in Figure 4 by the rightmost branch extending from the PT-QoL root node. This branch terminates at a node that contains a stack of ST-QoL objects representing the fact that the system outputs multiple ST-QoL predictions for each patient profile submitted to the system. Because the model is predicting

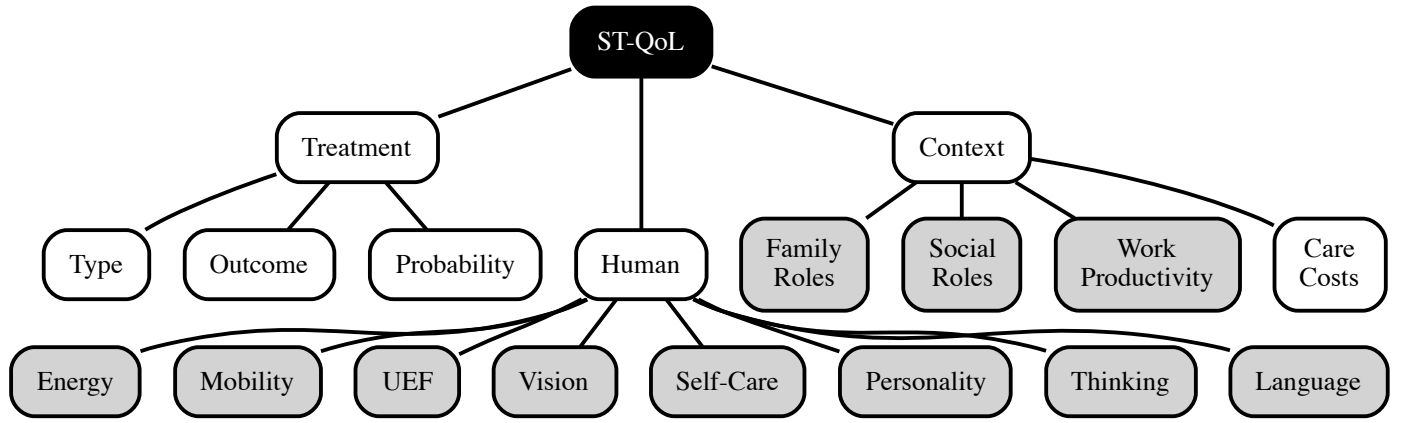


Fig. 3. Hierarchical grounding of the ST-QoL concept in concrete metrics.

structured objects (ST-QoL data structures) this prediction task is more complex than standard prediction problems and is technically known as *structured prediction* [19]. What this highlights is that the elements within an ST-QoL structure are interrelated and that it is not reasonable for a prediction model to predict each of these elements in isolation. Instead, the model needs to ensure that the predicted structure is self-consistent. For example, the model should not predict that the outcome of a particular treatment for a patient as being 0 on the mRS scale (indicating no symptoms) while at the same time predicting that the patient will have reduced vision or mobility.

Turning to the definition of the input features for this prediction task. Similar to the development of the ST-QoL definition in the previous section, our definition of the input features for this prediction task is also guided by the QoE framework. The initial level of decomposition of the input is in terms of the influence factors set out in the QoE whitepaper [6]: Human, Service, and Context.

The Human influencing factor is further decomposed into three sub-domain concepts: demographics, lifestyle and medical. These sub-domain concepts are then mapped to concrete measurable features that are relevant to the prediction of the patient's QoL post stroke treatment. The demographics domain concept encompasses information such as age and gender. The lifestyle domain concept includes information such as whether the patient is a smoker, do they exercise regularly, and have they recently taken part in very strenuous exercise that may have brought on the stroke. The medical domain concept includes the patient history, imaging data from CT or MRI scans, lab test results, Omics data (including for example genomic based risk factor calculations), and the patient's current status. The National Institutes of Health Stroke Scale (NIHSS) is a well-regarded clinical instrument used to quantify the impairment caused by a stroke [20]. It measures 11 factors, including (among others) a visual field test, facial palsy, arm and leg motor tests, and language and speech tests. Each factor is scored on a scale between 0 and 4 where 0 indicates no impairment and higher scores indicate increasing levels of impairment. The NIHSS has been shown to be a strong predictor of patient outcomes [21]. Consequently, we believe that this is an appropriate scale to use to represent the patient status.

The Service influencing factor models the treatment facilities available to a patient. Indicative features include the hospital resources, such as the treatments available at the hospital and the waiting times associated with treatments. Another aspect of patient treatment that needs to be considered is the rehab support available to the patient. Finally, the Context influencing factor models both the patient's social networks and their economic context. The social network concept encompasses features such as whether the patient has family or friends who can support the patient post treatment. The economic resources includes information such as whether the patient has health insurance. These contextual features are likely to be predictive of the care costs, and family and social roles components of the ST-QoL structure.

V. CONCLUSIONS

Stroke is the second most frequent cause of death in the world population [10]. More importantly for this work, stroke is also one of the principle causes of disability. It is because stroke can leave suffers with a wide-variety of long-lasting disabilities that it is important for clinicians to consider QoL during the treatment selection process. To help clinicians with this decision we plan to develop a CDS system that provides predictions of QoL for post-treatment stroke patients for each treatment-outcome, along with probabilities of each outcome.

This paper presents an initial framing of the problem of predicting the impact of treatment selection on QoL. This framing involved defining the ST-QoL data structure to relate treatment outcomes with QoL indicators. Furthermore, we set out how predicting ST-QoL can be framed as a machine learning structure prediction problem and grounded this prediction problem in a set of measurable input and output features. The definition of both the ST-QoL data structure and the input features to the ST-QoL prediction system was based on the distinctions set out in the QoE framework. We expect that the QoE framework can be useful in defining post-treatment QoL for a range of diseases, beyond stroke, and to this end we hope that this paper provides inspiration for other health researchers to adopt the QoE framework. Finally, we believe that the framework we set out in this paper has relevance to the multimedia QoE community. Specifically, the focus in our framework on modeling QoL as a multi-faceted interrelated

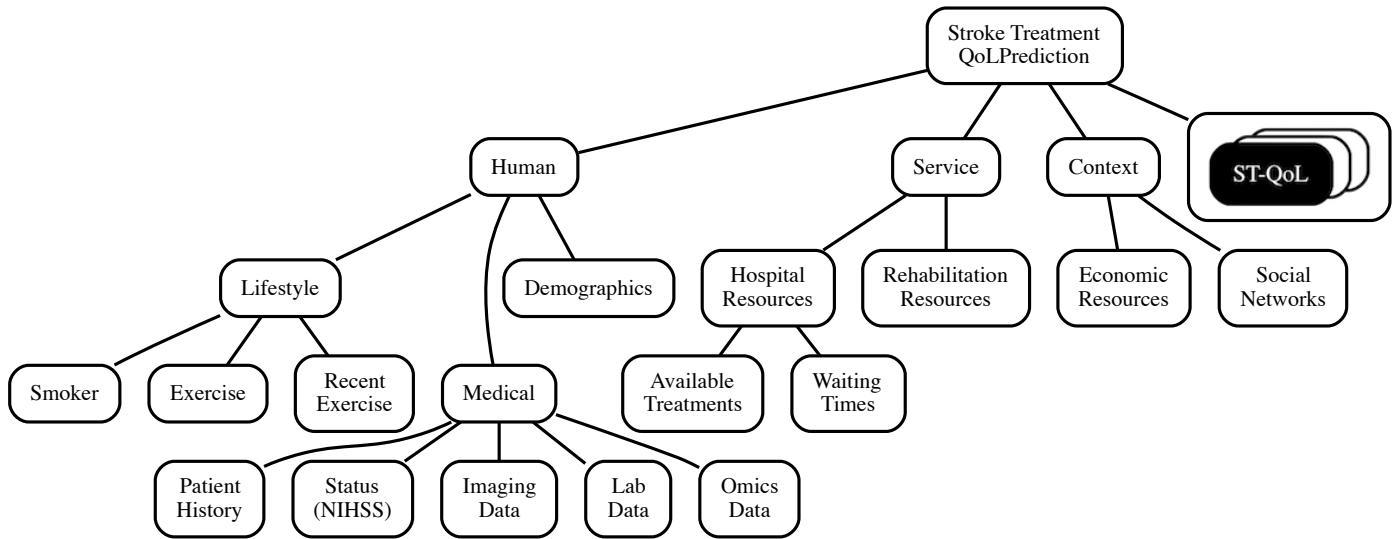


Fig. 4. Decomposition of the post-stroke treatment QoL prediction task

concept in terms of a structured prediction points to the measuring of QoE in a similar multi-faceted approach. Finally, we believe that the proposed framework has relevance to QoE prediction for the multimedia community, specifically the use of structured prediction to model multi-faceted interrelated concepts.

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